## **EXHIBIT J**

Declaration of Tonya Joiner, Assistant Secretary of the Office of Public Health within the Louisiana Department of Health

Case 3:25-cv-00025-KAC-JEM

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## IN THE UNITED STATES DISTRICT COURT FOR THE EASTERN DISTRICT OF TENNESSEE KNOXVILLE DIVISION

STATES OF TENNESSEE, ALABAMA, ) ARKANSAS, GEORGIA, IDAHO, INDIANA, ) IOWA, LOUISIANA, MONTANA, ) NEBRASKA, NORTH DAKOTA, OHIO, )	
SOUTH CAROLINA, SOUTH DAKOTA, and $\frac{1}{2}$	
WEST VIRGINIA,	
Plaintiffs,	Civil Action No. 25-cv-25
v. ,	
U.S. DEPARTMENT OF HEALTH AND ) HUMAN SERVICES; XAVIER BECERRA, in ) his official capacity as Secretary of Health and ) Human Services; and U.S. DEPARTMENT OF ) HEALTH AND HUMAN SERVICES OFFICE ) OF CIVIL RIGHTS,	
Defendants.	

## **DECLARATION OF TONYA JOINER**

Pursuant to 28. U.S.C. §1746, I, Tonya Joiner, duly affirm under penalty of perjury as follows:

- I am over 18 years of age, have personal knowledge of the matters set forth herein, 1. and am competent to make this declaration.
- 2. I serve as the Assistant Secretary of the Office of Public Health (OPH) within the Louisiana Department of Health.
- 3. OPH's Bureau of Family Health oversees a number of public health surveillance programs which are established by state law to promote the health and wellbeing of the people of Louisiana. Three of those vitally important programs are:
  - (1) The Louisiana Birth Defects Monitoring Program, established by LSA -R.S. 40:31.41-31.48, which collects, analyzes, and disseminates data

- regarding birth defects in Louisiana and provides information to families of affected children so that they can receive appropriate services.
- (2) The Louisiana Child Death Review Panel, established by LSA R.S. 40:2019, which collects data and conducts investigations into unexpected deaths of children below the age of fifteen with the goal of reducing the incidence of injury and death among such children.
- (3) The Louisiana Pregnancy-Associated Mortality Review (PAMR), an authorized activity of the Louisiana Commission on Perinatal Care and Prevention of Infant Mortality, established by LSA R.S. 40:2018, which collects and analyzes data for the conduct of maternal and infant mortality studies with the goal of reducing the number of teenage pregnancies, sick infants, and infant mortalities.
- 4. All three of these surveillance programs require the collection and abstraction of individual patient data related to maternal, infant, and child health. To that end, healthcare providers and other appropriate sources of needed information are statutorily required to provide these programs with access to relevant records upon request. See LSA R.S.31.43(B) (Birth Defects Monitoring Program); LSA R.S. 40:2019(F)(1) (Child Death Review Panel); LSA R.S. 2018(I)(1) (PAMR).
- 5. In furtherance of their responsibilities, the data abstractors for each of these programs historically have been able to request files and records for their case abstraction activities via mail, email, fax or by direct access to the electronic health records of the healthcare provider or other data source for data abstraction following each source's HIPAA policies and confidentiality rules. These sources have worked with the abstractors to comply with the data collection requirements for each program and reduce the administrative burden on staff to ensure records could be abstracted in a timely manner to support identification, prevention efforts, and linking families to resources. The approximate numbers of individual records requested annually by each program are as follows:
  - Birth Defects Monitoring Program: Over 2,000
  - Child Death Review Panel: Over 450
  - PAMR: Over 100

- 6. I am aware of the Department of Health and Human Services' HIPAA Privacy Rule to Support Reproductive Health Care Privacy, 89 Fed. Reg. 32,976 (Apr. 26, 2024) (the "Final Rule"), which took effect on June 25, 2024, with a compliance deadline of December 23, 2024. Specifically, the Final Rule places limits on disclosure and use of patient information "potentially related to reproductive health care," which it broadly defines as "health care...that affects the health of an individual in all matters relating to the reproductive system and to its functions and processes". 45 C.F.R. § 160.103.
- 7. The Final Rule is currently creating unnecessary barriers to the ability of these three OPH surveillance programs to access the individual records that they need in order to fulfill their statutory obligations.
- 8. Since the Final Rule became effective, some providers have asked the abstractors for these programs to complete attestations (as allegedly required by the Final Rule) before they provide access to records related to maternal PHI. Included among those providers is the largest birthing hospital in the state of Louisiana, which was the first to request an attestation from Birth Defects Monitoring Network staff. PAMR and Child Death Review staff have been able to continue accessing records using established remote access protocols, but have been asked to complete attestations when requesting records via email or fax.
- 9. Compliance with these requests for attestations, which are anticipated to increase in number as awareness of the Final Rule becomes more widespread, creates significant new administrative burdens for these programs, including time spent on completing the attestations. awaiting administrative approval before gaining access to the requested records, and consulting with legal counsel on issues related to the attestations. These burdens are increased by the Final Rule's requirement that a new attestation be provided for each specific records request.

10. Furthermore, the delays resulting from the process of complying with attestation requests and obtaining approval for data access can be anticipated to hamper the efficiency and effectiveness of the programs' data collection activities. The delays also will likely threaten their

ability to meet data abstraction timeliness requirements imposed by federal funding sources for

those activities.

11. These burdens, delays, and problems will only become more acute if the programs ultimately are required to provide attestations for all records that they request, including those for which they currently have remote access.

Tonya Joiner

Dated: February 5, 2025